

**Children's Special Health Services  
Family Advisory Council meeting minutes  
February 21, 2004**

Present from Family Advisory Council: Donene Feist, Cheryl Klee, Jennifer Restemayer, Lisa Beckman, Evelyn Klimpel

Present from CSHS: Terry Bohn, Tammy Gallup-Millner, Kora Dockter, Sue Burns,

## **Updates**

**Membership:** The two-year terms for the Advisory Council for Lisa, Lori, Donene, and Cheryl will expire effective with the May, 2004 meeting. Those individuals were asked to let Terry know about their interest in serving another term.

**Review/Recommendation Form:** Will be updated and made available for review at the May meeting

### **CSHS Program Updates**

- **Specialty Care.** There had been some concern about 2 eligible children with extremely high cost to the program. It appears that those costs will not be as high as originally thought. Claims payments are going well although there are some delays with recipient liability. CSHS is doing quality assurance activities. Staff attend Medicaid claims/policy meetings.
- **Multidisciplinary Clinics.** The authorization for cardiac clinics still has some problems. Due to declining numbers, CSHS may decrease the number of cleft clinics in Grand Forks to 2. There are currently 4 scoliosis sites; CSHS is checking numbers of attendees. CSHS added asthma as a contracted clinic. Staff have conducted site visits and provided technical assistance. In addition, CSHS staff have followed up on issues at the Grand Forks myelo clinic and are doing quality assurance with the metabolic clinic.
- **Care Coordination.** The Fargo site continues to provide service to about 30 children and there have been increased numbers in Grand Forks due to outreach and education activities in the community. CSHS workers in county offices continue to require ongoing technical assistance. It was recommended Community Resource Coordinators be contacted regarding providing referrals to CSHS.
- **Metabolic Program.** CSHS has served a consistent number of children and adults, although the program only serves women through age 44. There is a new gelatin product that is being provided. There is an issue related to coverage of disease specific formulas by Medicaid.
- **Data Systems Development:** A report from the ND Birth Defects Monitoring System was distributed. It was mentioned that January was designated as Birth Defects Prevention Month in ND, which resulted in media coverage about birth defects. Cheryl was recognized for her participation on the state's birth defects

workgroup. An update about activities related to the Title V needs assessment was provided. CSHS will be conducting a family survey and contracting to complete family focus groups and a provider survey. Donene helped to select the contractor. It was announced that Grand Forks would be conducting a regional needs assessment that will include information on CSHCN.

- Administration. The Health Department is applying for a CDC asthma planning grant. If received, the state's asthma program will switch from CSHS to the Health Department. Two staff people from Research and Statistics moved into the CSHS office space. CSHS spending is on track with budget projections so far this biennium.
- Public Information. The CSHS Public Information summary report from last year was distributed. Members commented that the new URL for the DHS website made it easier to find information about CSHS and child health. Three fact sheets from the Birth Review Program were reviewed.
- Medicaid. The Medicaid program will be distributing provider and recipient newsletters. Prevention for adults is a new focus within Medicaid. Donene mentioned an increase in calls to Family Voices related to Medicaid reimbursement of therapy services. An evaluation Medicaid's Targeted Case Management Program was reviewed.

### **Family Voices Meeting**

Donene reported on a national Family Voices meeting she and Twyla attended. Donene discussed improvements to the Family Voices database for Health Information Centers. There was discussion about family members conducting the CSHCN questions in the next SLAITS survey. Donene also discussed information she received on train the trainer for child abuse for CSHCNs and advocacy.

### **Shriner's Hospital**

Lisa will be attending an appointment at the Shriner's Hospital soon. She will keep the Council informed about any upcoming changes.

### **CSHS Family Survey**

Members reviewed the draft of the CSHS Family Survey. Members suggested changes to questions about out of pocket costs (Section VI), out of state care, and additions to the list of programs and services. Those changes will be made to the final survey before being sent to families to complete. Donene will pretest the survey with 20 families.

### **CSHS Family Handbook**

Council members and staff discussed a draft of the CSHS Family Handbook. The following suggestions were made:

- Check all references to the DHS website for accuracy
- Cite sources to sections were needed

- Credit the site where the model for the Handbook came from
- Incorporate county contact information
- Remove the “you owe \$\$” graphic
- Printing could be done on the CSHS color printer
- Include a revised date
- Reference publications (i.e. Angry? Confused? Overwhelmed?)
- Include page numbers
- Include toll-free numbers for family support programs/organizations
- Spell out acronyms & abbreviations

### **Katie Becket Waiver**

It was announced the ND Disability Advocacy Consortium may work to apply for a waiver.

### **Open Forum – Family Needs Assessment**

Members discussed the following issues:

- Vocational Rehabilitation (VR). Students need to fill out forms to estimate family financial contribution before being eligible to receive VR services. VR provides limited help for college expenses. VR accepts clients who could potentially hold jobs or be successful in post-secondary education. High schools are not doing the last full evaluation before college so there is no current information while at college. Schools should test kids their senior year and get them hooked up with VR. VR is more likely to serve those with more severe disabilities. Ticket to work is an option to go to a provider of choice.
- Early Intervention. There is a gap in services for children after age 3 who no longer can receive early intervention and are not found eligible for developmental disabilities or other programs.
- Insurance Coverage. Some physicians are prescribing vitamin supplements for some conditions that are not covered by insurance. Families can buy their own insurance but it will not always cover health expenditures. Members suggested 5-10 % of income was a reasonable percent of family income to pay for insurance premiums. Insurance sometimes excludes pre-existing conditions. Policies can have high-cost premiums, or riders, to get minimal coverage
- Medicaid Coverage Groups. Children on SSI are in the Medicaid disability group – not the family coverage group – so there still is an asset test for eligibility. Children in the medically needy coverage group often have a high recipient liability.
- Gaps in Services. Some children on IEPs graduate from high school with their peers before age 21 and they cannot access needed services. More information about options needs to be provided to the students and their parents.
- Guardianship. Parents need more information about when guardianship is appropriate for their child when they turn 18.
- Durable Medical Equipment (DME). DME often not covered well.

- Providers. Most providers are well intentioned and have their patient's best interests at heart but lack time and expertise to coordinated services for child and family.

### **ND Family Connections Conference**

The ND Family Connections Conference is scheduled for June 10-12, 2004 in Fargo. More information about the conference is at <http://www.conted.und.edu/connections/>

### **Next Meeting**

The next meeting of the CSHS Family Advisory Council will be Saturday May 15, 2004